CLINICAL RESEARCH STUDY

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Restricting Symptoms Before and After Admission to Hospice

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ABSTRACT

BACKGROUND: Prior work has shown that symptoms leading to restrictions in daily activities are common at the end of life. Hospice is a Medicare benefit designed to alleviate distressing symptoms in the last 6 months of life. The effect of hospice on the burden of such symptoms is uncertain.

METHODS: From an ongoing cohort study of 754 community-dwelling older persons, aged ≥70 years, we evaluated 241 participants who were admitted to hospice from March 1998 to December 2013. A set of 15 physical and psychological symptoms leading to restricted activity (ie, cut down on usual activities or spend at least half the day in bed) were ascertained during monthly telephone interviews in the year before and 3 months after hospice admission.

RESULTS: The prevalence and mean number of restricting symptoms increased progressively until about 2 months before hospice admission, before increasing precipitously to a peak around the time of hospice admission. After the start of hospice, both the prevalence and the mean number of restricting symptoms dropped markedly. For several symptoms deemed most amenable to hospice treatment, including depression and anxiety, the prevalence dropped to levels comparable to or lower than those observed 12 months before the start of hospice. The trends observed in symptom prevalence and mean number of symptoms before and after hospice did not differ appreciably according to hospice admission diagnosis or sex. The median duration of hospice (before death) was only 15 days.

CONCLUSION: The burden of restricting symptoms increases progressively several months before the start of hospice, peaks around the time of hospice admission, and decreases substantially after the start of hospice. These results, coupled with the short duration of hospice, suggest that earlier referral to hospice may help to alleviate the burden of distressing symptoms at the end of life.

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Toward the end of their lives, many patients point to the alleviation of distressing symptoms as their most pressing need.[1,2] A recent Institute of Medicine report, however, found that symptom management at the end of life is often inadequate.[3] Despite calls to address this inadequacy,[4-6] the problem has gotten worse in the last decade. The prevalence of the most distressing end-of-life symptoms increased between 1998 and 2010 and remains high today.[7-9] Furthermore, symptom burden steadily increases during the last year of life.[10]

One of the most common approaches to ameliorating distressing symptoms is palliative care. Prior studies have shown that palliative care can significantly improve quality of life and even increase survival rates.[11-14] At the end of life, hospice, a specific type of palliative care, is often considered. Hospice use has grown substantially in the past decade. However, the median length of stay in hospice has remained very short, at approximately 2.5 weeks.[15] Because

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a primary objective of hospice is to provide symptom relief in the last 6 months of life,[16] this short duration raises concerns about whether hospice is being properly utilized.

Although the literature is replete with studies on hospice, relatively little is known about the course of distressing symptoms before and after the start of hospice. Prior studies of distressing symptoms at the end of life have focused on specific subgroups, such as patients with cancer,[17] have lacked data on hospice,[18] have not had access to detailed longitudinal data before hospice,[19] or have focused on only a single symptom, such as pain.[20] In an earlier study,[10] we used a longitudinal cohort design to study symptom burden in the last year of life. To our knowledge, comparable longitudinal data do not exist for patients before and after admission to hospice.

CLINICAL SIGNIFICANCE

- The burden of restricting symptoms at the end of life decreases significantly after the start of hospice, irrespective of hospice admission diagnosis.
- Median survival after hospice admission is very short.
- Earlier referral to hospice may help to alleviate the burden of distressing symptoms at the end-of-life.

In the present study, we set out to evaluate the course of symptoms before and after hospice admission. We were particularly interested in determining whether the occurrence of restricting symptoms (ie, those that lead to bed rest or cause one to cut down on activities) is reduced after the start of hospice. To address this question, we used data from a unique longitudinal study that includes monthly assessments of restricting symptoms before and after the start of hospice. Given the wide range of symptom severity, we focused on restricting symptoms because they are the most likely to be important for patients and their caregivers. We categorized these symptoms on the basis of clinical judgment into three groups, from most to least amenable to hospice treatment. Given previously reported differences in hospice referral, utilization, and functional decline at the end of life,[21-24] we also evaluated the monthly occurrence of restricting symptoms according to hospice admission diagnosis and sex as a secondary aim.

METHODS

Study population

Participants were drawn from an ongoing longitudinal study, previously described in detail,[25] involving 754 older persons. Eligible participants were community-dwelling, nondisabled, and aged ≥70 years at the time of enrollment. Exclusion criteria were substantial cognitive impairment with no available proxy, life expectancy <12 months (at the time of eligibility assessment), plans to move out of the area, or inability to speak English. Of the 1002 persons eligible for the study, 754 agreed to participate and were enrolled between March 1998 and October 1999. The research protocol was approved by the Yale Human Investigation Committee.

Analytic Sample

We identified 260 hospice admissions through 2013 using Medicare claims data and review of medical records.[26,27] Of these, 12 had previously dropped out of the study and 1 had died before their first monthly interview. To permit pre−post comparisons, 6 additional participants were excluded because they did not have at least 6 months of symptom data before hospice admission, leaving 241 participants in the analytic sample.

Data Collection

Comprehensive home-based assessments were completed at baseline and subsequently at 18-month intervals, whereas telephone interviews were completed monthly. During the comprehensive assessments, data were collected on demographic characteristics, depressive symptoms (Center for Epidemiological Studies Depression Scale[28] score ≥16), cognitive impairment (Folstein Mini-Mental State[29] examination score <24), and the presence of 9 self-reported, physician-diagnosed comorbid conditions: hypertension, myocardial infarction, heart failure, stroke, cancer, diabetes mellitus, hip fracture, arthritis, and chronic lung disease. Body mass index was calculated using participants' self-reported height and weight. For descriptive purposes and to fulfill federal regulations regarding the inclusion of minority participants in studies funded by the US National Institutes of Health, participants were asked to identify their race and ethnicity.

Hospice admission diagnosis codes were obtained from the Medicare claims data.[26,27] These diagnoses were classified into 7 categories (**Table 1**) based on the Centers for Medicare & Medicaid Services *International Classification of Diseases*, 9th Revision diagnosis codes. For 3 participants without Centers for Medicare & Medicaid Services Medicare claims data, the hospice admission diagnoses were inferred from information obtained from death certificates, which were coded by a certified nosologist.

Assessment of Restricting Symptoms

During the monthly interviews, the occurrence of restricting symptoms was ascertained using a standard protocol that has been previously described.[25] First, participants were asked 2 questions related to restricted activity: "Since we last talked (ie, during the last month), have you stayed in bed for at least half a day due to an illness, injury, or other problem?" and "Since we last talked, have you cut down on your usual activities due to an illness, injury, or other problem?" Second, if participants answered "yes" to either of these questions, they were asked whether they had any of